

Family Caregiving in an Aging Society

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The field of research on family caregiving extends back forty years, evolving from early studies of the 1950s and 1960s looking at the family unit in general; to studies in the 1980s and early 1990s focusing on specific caregiving activities, roles and responsibilities; to the current emphasis on understanding the processes and impacts of caregiving across different physical and mental conditions and ethnically diverse populations. We have progressed from small descriptive studies of available caregiving populations – usually service utilizing – to larger local area and national studies of random samples. Methodology and instrumentation have similarly improved, with current study designs and analyses being more sophisticated and comprehensive. The result is that we have considerable knowledge about who needs care, who receives care, who provides this care, what care is provided, the costs of care, and the impacts of this care on the caregiver. This paper summarizes what we have learned from many studies on informal caregiving, identifies issues in need of further study, and discusses the implications of empirical data for selected policy and practice issues regarding long-term care for frail older individuals.

Who Needs Care

Nearly one-quarter (22.9%) of all people aged 65 and over in this country are functionally disabled or currently in need of some form of long-term care (American Academy of Actuaries, 1999; Doty, 1986; NCHS, 1987). According to a monograph recently released by the American Academy of Actuaries (1999), the best care scenario projects that by the year 2040 the population of severely disabled (i.e., ≥ 3 ADLs) elderly will increase by 90%. This means that they need help with personal activities of daily living (bathing, eating, dressing, toileting), with instrumental activities of daily living (cooking, cleaning, laundry, transportation, etc.), with transfer or mobility, or they require skilled care of the sort provided by home health care agencies or nursing homes. Data have revealed that 1.2 million fewer older adults in 1994 were disabled than had been expected based on previous rates, but the actual scenario takes this recent trend into consideration. However, although the rates are lower, persons turning 65 (in 1996) can expect 5.3 years of dysfunction characterized by acute or chronic illness.

Who Receives Care

To be distinguished from who needs care is who receives care. Whether some older people are more likely than others to receive informal care at all, or to receive greater amounts of assistance, has implications for appropriate targeting of services to

subgroups with unmet need, or with patterns for service delivery to certain subgroups. Looking first at the likelihood of receiving informal care, noteworthy differences emerged when those people who rely on formal services for most of their care are compared with those who receive all of their help from informal caregivers. We have found that those who were not married, lived alone, and lived in public housing were less likely to have informal caregivers available for assistance and therefore more likely to rely on formal services for assistance. This describes the typical senior housing resident (McKinlay and Tennstedt, 1986).

Turning to variations in the levels or amounts of informal care provided, differences have been associated with the degree of disability, the gender of the elder, as well as with the elder's living arrangement. Most studies report a direct relationship between *the elder's degree of functional disability* and receipt of informal care (Sherwood et al., 1981; Horowitz and Dobrof, 1982; Branch and Jette, 1983). That is, those elders with the most impairment receive significantly more informal care than those who are minimally or moderately impaired (McKinlay and Tennstedt, 1986). It is interesting, however, that an expected simple linear relationship between level of frailty and receipt of care, where moderately impaired elders receive more care than minimally impaired elders, was not apparent in this study conducted in Massachusetts (Figure 1). Minimally and moderately impaired elders received similar amounts of informal care, indicating a possible threshold of impairment, at which the amount of such care increases substantially. This apparent threshold may be related to: a) an increase in the number and scope of needs, necessitating a wider variety of help and more intensive care; b) a preference by elders for care by their families; c) the family's sense of responsibility for providing care; d) the greater ability of informal care to meet specific needs (e.g., flexibility in response, intimate knowledge of elder); and/or e) problems with access, availability, or limitations of formal services (e.g., restricted hours/functions, staff shortages, reimbursement issues). Further, the receipt of informal care increases far more dramatically than the use of formal services with an increase in disability. These data underscore the predominance of informal care even at a point when use of more formal services might be expected.

Gender clearly influences the type and amount of informal care received. While women are more likely than men to receive help from informal caregivers, it does not appear that they also receive more such care. Consistent with other findings (Branch and Jette, 1983), our Massachusetts data indicate that, controlling for functional status, men receive more care than women (Tennstedt and McKinlay, 1989). This finding may be a function of the time required to perform gender specific types of care received. Older

men are more likely to receive help with personal care, housekeeping tasks, and meals, activities which may require more time than the assistance with transportation, shopping, and home repairs which were more frequently received by women. In addition, while men receive more care, on average they are likely to get that help from only one person, usually their spouse. Older women, on the other hand, have larger numbers of caregivers, typically two to four.

These differences in types and related amounts of assistance received are probably related to both traditional gender/social role behavior, as well as the influence of gender/social role stereotypes on perception of need for help. Older people most likely continue to do those tasks of daily living with which they feel familiar, and for which they have skills, and to receive help in those areas with which they are unfamiliar or less skilled. Conceptual models of utilization behavior (e.g., Anderson and Newman, 1973; Mechanic, 1962) have often related use of services to perceived need, as distinguished from objective need determined by functional assessment of health indicators. Older men and women appear to perceive their need for assistance differently. One male respondent who was physically able to perform household tasks, yet received substantial help, told us that he would rather starve than learn to cook his own meals! Similarly, caregivers' expectations of the elder may differ according to the elder's gender, and therefore be an additional determinant of the type of informal care provided. For example, caregivers may be more likely to provide meals for older men because they do not expect them to cook for themselves.

Finally, our data and that of others indicate that an *elder's living arrangement* is an important predictor of the level of care received (Tennstedt and McKinlay, 1989). Elders living with a spouse (78 hours/week) or others (66 hours/week) were likely to receive substantially more care than those who lived alone (9 hours/week). Our data also indicate that those living alone are nearly twice as likely to use paid formal help (Tennstedt et al., 1993a). It should be noted that living alone has consistently emerged in studies as a major predictor of institutionalization of the elderly (Shanas, 1979; Kahana and Kiyak, 1980; Prohaska and McAuley, 1983), having important implications for identification of subgroups most in need of community services.

Who Provides Care

Families have always been and continue to be the primary source of help to disabled elders. It is estimated nationally that family and friends are the sole source of assistance for nearly three-quarters of impaired older adults in the community (Doty, 1986). They are also the preferred source of help for most elders (Shanas et al., 1968;

Comptroller General of the U.S., 1977; Eggert et al., 1977; U.S. DHEW, 1978; Cantor and Johnson, 1978; Community Council of N.Y., 1978; Branch and Jette, 1983; McAuley and Arling, 1984; McKinlay and Tennstedt, 1986; Stone et al., 1987).

In 1996, the National Alliance for Caregiving and AARP conducted a nationwide telephone survey to identify and profile the experiences of caregiving (National Alliance for Caregiving and American Association for Retired Persons, 1997). This survey provides the most recent national data on a random sample of households in the U.S. The sampling strategies ensured the inclusion of minorities and enabled the identification of caregivers for persons age 50 and over with a variety of disabling conditions. This data set provides our most current prevalence estimates of caregiving – the experiences and impacts. Based on results of this survey, nearly one in four U.S. households with a telephone contained at least one caregiver (defined as currently or previously providing care within the last 12 months to a relative or friend at least 50 years old). This translates into 22.4 million caregiving households nationwide during the 12-month period of study.

The findings of the NAC/AARP study are overwhelmingly consistent with data from earlier studies. The majority of caregivers are women. The NAC/AARP study reports that 72.5% of the national sample of caregivers were female. Any small differences in gender in other studies is likely related to the age inclusion criterion for the care recipient. Average age of caregivers is similarly influenced by the age of care recipients – the older the care recipient, the older the caregiver.

Consistently across all studies of caregiving and as has been reported in the NAC/AARP study, spouses are the first source of caregiving assistance. Likely related to the nature of the marital relationship, spouses are often the sole caregiver (Stone, Cafferata and Sangl, 1987; Tennstedt, McKinlay and Sullivan, 1989) and provide the most extensive and comprehensive care (Cantor, 1983; Horowitz, 1985; Johnson, 1983; McKinlay and Tennstedt, 1986; Shanas 1979; Soldo and Myllyuoma, 1983; Stephens and Christianson, 1986; Stone, Cafferata and Sangl, 1987). This holds true for caregivers of elders with dementia or with functional disabilities only. Offspring are usually the next source of informal care, also for both groups, with daughters more likely than sons to be in this role. Friends and neighbors are mobilized in the absence of family caregivers, or as supplemental sources of assistance (Cantor and Johnson, 1978; Sherwood et al., 1981; Shuval et al., 1982; Stoller and Earl, 1983; McKinlay and Tennstedt, 1986). However, caregiving for elders with dementia is less frequent among extended kin or non-kin, likely because of the greater commitment and involvement required.

An important point about gender and relationship of caregivers. While females predominate in the role, our longitudinal study in Massachusetts has reported that spousal

caregivers are just as likely to be male as female (Tennstedt et al., 1993a). Further, these men were more likely to be the sole caregiver, with no assistance from others (Tennstedt et al., 1989). That is, male spousal caregivers are similar to female spousal caregivers.

Data have shown that generally caregiving is not a shared activity. Consistent with several other studies (Horowitz, 1978; Frankfather, Smith and Caro, 1981; Horowitz and Dobrof, 1982; Johnson, 1983; Stoller and Earl, 1983; National Alliance for Caregiving and American Association for Retired Persons, 1997), we found that one person tends to provide the majority of informal care. Secondary caregivers are often few in number and provide much less care, and then on an intermittent basis. Further, our data indicate that women – usually daughters – caregivers are more likely than men to receive assistance from others in caring for the older person and that these secondary caregivers are often the caregiver's spouse and children (Tennstedt et al., 1989). This focusing of caregiving responsibilities on a nuclear family unit has obvious implications for potential negative impact, which may, in turn, contribute to increased risk of institutionalization of the elder.

Caregivers typically live in close proximity to the care recipient. The NAC/AARP survey (1997) reports that 20% share a household and another 55% live less than 20 minutes from the care recipient. This proximity clearly facilitates the provision of care. A decision to coreside is often related to the elder's need for care. However, residential proximity likely also influences who in an extended family assumes the primary caregiving role. If there is a choice, the adult child who lives close by and has few competing responsibilities (not employed, not married, few or no children) is the likely candidate.

In the last 10 years, there has been increasing attention to differences in caregiving across ethnic groups. The early comparative studies focused primarily on comparisons of African-Americans and Whites. More recently, researchers have studied Hispanic and Asian subgroups as well. The NAC/AARP survey (1997) included Whites, Blacks, Hispanics, and Asians. They reported higher incidence of caregiving among Asian-American (31.7%), African-American (29.4%) and Hispanic (26.8%) households than in the general population. The larger and modified extended families of African-Americans and Hispanics are thought to increase the informal care resources of older persons in these two groups (Chatters et al., 1985, 1986; Montgomery and Hirshorn, 1990; Delgado and Humm, 1982). In fact, caregivers in these three minority groups are more likely than in the general population to provide care for more than one person. They were also more likely than White caregivers to live with the care recipient and to have help from other persons (National Alliance for Caregiving, 1998).

Types and Amounts of Informal Care

Studies have shown that informal caregivers provide a wide variety of assistance, with emotional support often cited as the most common activity (Horowitz and Dobrof, 1982; Shuval et al., 1982; McKinlay and Tennstedt, 1986; Stone et al., 1987). As displayed in Table 1, caregivers in the NAC/AARP study provided help with many instrumental tasks. Data in Table 2, however, indicate that help with personal care is less frequent. Although sometimes mentioned, generally financial contributions are not an important type of assistance, although out-of-pocket expenses may be incurred in providing care. It appears that families are more inclined to provide services directly than to purchase them for the elder (Horowitz and Dobrof, 1982; McKinlay and Tennstedt, 1986). However, recent data from the NAC/AARP survey (1997) show that caregivers in higher income categories are more likely than those with less income to purchase in-home services.

The type of care provided by a specific caregiver appears related to gender-expected activity. Female caregivers typically provide personal care, housekeeping tasks, and meals, while male caregivers provide assistance with home repairs, transportation, and financial management (Treas, 1977; Horowitz and Dobrof, 1982; Stoller and Earl, 1983).

However, one cannot assume that because women are more likely to provide care, that they also provide larger amounts of care. Only a few studies have explored whether the actual amount of care varies by the caregiver's gender, and the results of these studies are less consistent (Stoller and Earl, 1983; McKinlay and Tennstedt, 1986; Stone et al., 1987). In our sample (Tennstedt et al., 1993a), we found that male and female spousal caregivers provided similar amounts of care. However, all other female caregivers were found to provide considerably more help than male caregivers. Similar results were found in the National Long Term Care Survey (Stone et al, 1987) and in the National Alliance on Caregiving/AARP Study (1997). However, while observing these gender differences, it should be noted that both groups provide substantial amounts of care. According to the nationwide NAC/AARP Survey (1997), on average caregivers spend 18 hours per week on caregiving, with almost one-fifth (18.6%) of caregivers providing constant care for 40 or more hours per week. The difference in hours may well be a function of the time and frequency of contact required to provide different types of care (e.g., meals vs. home repairs). This underscores the importance of considering both type and amount of care when examining differential impact of helping activities on the caregiver.

Differences in amounts and types of care are directly influenced by the type and extent of the care recipient's impairment. The care recipient's profile of need for care can be based on duration (acute vs. chronic) or type of impairment (physical vs. cognitive vs. combined). Most acute situations involve physical conditions and require care provision at potentially high levels for time-limited periods. Sometimes these situations do not even get defined as caregiving by those providing assistance because of the short duration. They are considered similar to care of any illness or injury of a family member of any age. The situations defined as caregiving usually involve chronic conditions necessitating long-term care, including both physical and cognitive impairments. A distinction between dementia care and non-dementia care has been made by researchers recently to study differences in the caregiving experiences. According to NAC/AARP (1997) data, 22% of caregivers report that their care recipients suffer from dementia. As would be expected, dementia caregivers provide more hours of care (19.0 vs. 12.5 hrs), more types of care, and were more likely to help with personal ADLs than were non-dementia caregivers (National Alliance on Caregiving and Alzheimer's Association, 1999).

The proximity of the caregiver to the care recipient is a critical factor in determining the pattern of care. In particular, if the caregiver and care recipient coreside, there will be greater caregiving involvement and less use of formal services (Chappell, 1991; Diwan, 1997; Tennstedt et al., 1993a), regardless of caregiver relationship (Tennstedt et al., 1993a). Coresidence is more likely for dementia caregivers, especially at later stages of disease, which likely accounts for the greater caregiving involvement when compared to all non-dementia caregivers. Yet, the relationship between coresidence and lower use of selected dementia services has also been reported (Gill et al., 1998). Proximity to the care recipient is less of an issue in the provision of short-term or "crisis" care. Himes and colleagues (1996) have reported no difference in amount of care by those living with or very near the care recipient and by those caregivers more distant when the care was for a time-limited period. This is less relevant for primary caregivers in the care of elders with dementia, underscoring the importance of proximity or coresidence in the provision of care.

The employment status – a competing responsibility – of the caregiver has been related to the level of care provided, but results across studies have been quite inconsistent. However, most studies including the NAC/AARP survey (1997) report that employment has no effect on the amount of care provided. Instead, it appears that employed caregivers make accommodations in their work schedule or arrangements in order to meet caregiving responsibilities.

Ethnic or racial differences in types and amounts of care have also been studied. At the bivariate level, many studies (National Alliance on Caregiving and American Association for Retired Persons, 1997; Hays and Mindel, 1973; Cantor, 1979; Mitchell and Register, 1984; Tennstedt et al., 1998) have reported that minority caregivers provide more care than do White caregivers. Typically, cultural differences (e.g., greater familial reciprocity) have been assumed to account for this. Others assert that the increased disability of minority elders accounts for higher levels of caregiving. In our cross-cultural comparative study, we found that even when controlling for disability, caregivers in the two minority groups provided more care than did White caregivers (Tennstedt and Chang, 1998).

It is commonly thought that the size and composition of the caregiving network influences the organization and provision of care. Larger networks of caregivers, closely related and/or very committed to providing care, are thought to result in sharing of caregiving responsibilities. This would seem particularly relevant in care for elders with dementing illness for whom needs for care are frequently great. The composition of the caregiving network evolves over time, influenced by the age, gender and race of the care recipient, but is generally stable (Peek et al., 1997). Burton and colleagues (1995) have reported that the number of caregivers does not differ by race although others have reported that minority elders have more caregivers due to the involvement of modified extended families (Chatters et al., 1985, 1986; Miller et al., 1994; Hatch, 1991; Cox and Monk, 1990).

Yet in light of these data, it has been reported consistently that the primary caregiver provides most of the care. In a study by Stommel et al. (1995), which included both dementia and non-dementia caregivers, the primary caregiver provided assistance with IADLs almost exclusively, but help with ADLs was shared with others. Data from this study revealed no specific threshold at which secondary caregivers are involved, but involvement was more likely when a high frequency of care was needed. The primary pattern of division of labor was one of supplementation, i.e., that secondary caregivers shared the responsibility for specific tasks with the primary caregiver rather than a splitting up of tasks (or specialization) among the caregivers. Other data reported by these investigators (Stommel et al., 1998) indicate that division of labor is influenced by race. Consistent with the larger caregiving networks of African-Americans, these caregivers are more likely than White caregivers to share care with secondary helpers but again remain involved in most activities.

Interface of Informal and Formal Care

Division of labor also extends to the involvement of formal service providers. This interface between the informal and formal sources of care has been of public policy interest in response to the concern that changing social trends – smaller family size, increased geographic mobility, greater participation of women in the work force, and rising rates of marital disruption – will decrease the availability or willingness of family members to provide care to a disabled elder. Division of formal and informal labor is of concern from a clinical perspective in terms of timely and appropriate use of formal services to ensure the well-being of both care recipient and caregiver.

To address the first question, longitudinal data from the Massachusetts Elder Health Project (Tennstedt et al., 1993) were analyzed to determine if formal services ever replaced or substituted for informal care. We did find evidence of replacement of informal care by formal services in <20% of cases. This occurred when there was a change in the informal caregiving arrangement, particularly loss or change in the primary caregiver. It was also more likely if the primary caregiver had not been a close relative. Typically, the change or loss in caregiver was due to illness or death (an involuntary situation) of the caregiver rather than to competing demands as had been speculated. The data also indicated that this substitution of formal services for informal care was temporary and that informal care was again in place by the next contact. The data from this study show that service substitution is not a major trend and support the fact that formal services are being used as intended. This study was conducted in a state with a well-established, publicly funded home care program, which would have made substitution of formal services for informal care easier. However, the fact that service substitution was temporary and related to availability of the primary caregiver suggests that public funding for home care does not result in widespread and undesired service substitution. There were no data to suggest that large numbers of families were voluntarily withdrawing their help in favor of formal service use. Rather, these publicly funded services appear to be doing what they are intended to do: supporting and sustaining the informal caregiving arrangement or providing care during the disruption of this arrangement to keep the elder in the community.

More recently, data from the HCFA-funded Medicine Alzheimer's Disease Demonstration show consistent results for dementia caregiving situation (Yordi et al., 1997). This three-year study investigated the effects of expansion of community-based services and case management to over 5000 caregivers of dementia clients to test the effect of service expansion on levels of informal care. In a randomized trial, caregivers in the treatment group used slightly more care over time. However, there were no differences in primary caregiver hours or in the number of tasks by primary or secondary

caregivers between caregivers in the treatment group vs. control group. An important finding in this study is the value of case management. That is, a decrease in the number of unmet needs and a better match between assistance needed and services received in the treatment group suggests that case management was beneficial.

In general, formal services are used by relatively few caregivers and care recipients. National data from both the Supplement on Aging to the National Health Interview Survey and the 1982 Long Term Care Survey show that only a small proportion (9% and 5% respectively) receive all their care from formal, community-based providers (Doty, 1986). Further, only 26% of this formal community care is government financed. The remainder is privately paid by older people themselves and their families (U.S. Bureau of the Census, 1983; Soldo, 1983; Liu, Manton and Liu, 1986). Clearly, the vast majority of long term care is provided informally, and privately, at no public cost.

The involvement of a coresiding caregiver consistently has been related to lower use of formal services by elders with (Gill et al., 1998) and without dementing illness (Tennstedt et al., 1993a, 1996). Initial use, or increased use, of formal services usually occurs in the presence of informal care but when care needs increase or when there is a change in the primary caregiver (Tennstedt et al., 1993b, 1996). The use of formal services is more likely when the elder has ADL deficits (Diwan et al., 1997). There are no published longitudinal data about these transitions in dementia care. Similar to findings for elders with physical disabilities, cross-sectional data indicate that use of formal services is greater by elders with dementia who have greater functional impairment, live alone, and have higher incomes (Bass et al., 1992; Caserta et al., 1987; Gill et al., 1998; Mullan, 1993; Penning, 1995). Finally, use of services is lower among minority elders and caregivers than for White caregiving dyads (Tennstedt et al., 1998).

Costs of Care

Costs of care for elders with and without dementia have also been studied, with estimates made of the value of the informal care provided. Several years ago, Massachusetts Elder Health Project (MEHP) data were used to estimate costs of care for community-residing disabled elders (Harrow et al., 1995). The cost of informal caregiving hours was calculated using a market value approach. The costs of formal services were calculated using actual hourly rates for each type of service used. The total economic costs of community care (both informal care and formal services) were estimated at \$9,552/year (in 1991 dollars). About 80% of these costs were for informal care, representing no expenditure of real dollars by individuals or by the government. As might be expected, cost estimates for informal care of elders with Alzheimer's Disease

are substantially higher, estimated by others in 1991-1992 to be between \$43,600 (Max et al., 1995; Rice et al., 1993) and \$38,900 (Weinberger et al., 1993). Similarly, from 80-90% of these costs were for informal care.

The MEHP cost estimates for type of care provide an interesting picture of how resources, both informal and formal, are being spent on community care. There is a consistent pattern over time, and for both informal care and formal services, for the majority of resources to be spent on housekeeping, personal care, and meals, in that order. Of interest here is that the majority of *both* informal and formal resources are expended in these areas of care. In other words, formal services are used to supplement care provided informally rather than to complement the informal care. This suggests that formal services are used where needs are greatest rather than to provide care for which services are best suited as proposed by Litwak (1985). These results also suggest that demand for services, particularly if the availability of informal care is diminished in the future, will be the greatest for home health aides, homemakers, and home delivered meal services.

MEHP data were also used to compare cost of community care to that of nursing home care. Two scenarios were compared to nursing home costs: 1) total actual costs of informal care and formal services, and 2) a simulation of all care provided by formal services only (Table 3). Average cost of nursing home care in Massachusetts in 1991 was \$35,522. As previously stated, actual total costs of community care (both informal and formal) was \$9,552. However, if all of this care were provided by formal services, the cost would be \$13,799. While these costs for formal services are almost 50% higher than for combined informal care and formal services, the costs for meeting all of the elder's needs with formal services was less than half the cost of nursing home care. Even adding \$7,200 for out-of-pocket expenditures on food and shelter, as taken from the Consumer Expenditure Survey (U.S. Bureau of the Census, 1992), community care was still less expensive than nursing home care for most disabled elders. It was only when an older person was severely disabled and required about 40 hours of care per week (equivalent to a full-time job for a caregiver) did the cost of community care plus living expenses approach or exceed the cost of nursing home care.

Most recently, the NAC/AARP data were used to develop a national estimate of the economic value of informal care (Arno et al., 1999). Using a market wage approach and a single wage rate, they developed three estimates – low, mid-range, and high – of the value of care (Table 5). Based on 17.9 weekly hours of care at \$8.18 hourly wage and 25.8 million caregivers, the mid-range national estimate of the economic value of informal care in 1997 was \$196 billion. Comparing it to available national spending for

home care (\$32 billion), nursing home care (\$83 billion), and total health care (\$1,092 billion), we see that the economic value of informal care is equivalent to approximately 18% of national health care spending and exceeds spending for home care and nursing home care combined.

Impacts of Care

For many years, researchers have focused on documenting burden among caregivers, and then on identification of which caregivers were most likely to be burdened. The personal, social, and health impacts of caregiving have now been well documented. However, it is critical to look separately at caregivers for elders with and without dementing illness. Their experiences are different. We must be careful not to generalize to all caregivers what we have learned about dementia caregivers. Most of the early studies of caregiver burden were of dementia caregivers. These early studies were often of non-representative samples identified through service agencies – caregivers who were more likely to be stressed. Measurement was less sophisticated in these early studies. The rates of burden reported from these studies were alarming and unfortunately were generalized to all caregivers. Questions were developed for these studies that asked directly about the stresses of caregiving. Measures in more recent studies include general physical and emotional health indicators of stress, such as depression, sick days, and health care utilization.

Given these multidimensional issues, what has been reported consistently across studies, including the recent NAC/AARP survey, is the constraints or restrictions of caregiving on time for leisure, social and personal activities (National Alliance for Caregiving and Alzheimer's Association, 1999; McKinlay et al., 1995). Table 4 displays negative impacts for dementia and non-dementia caregivers. Overall, 55% of caregivers reported less time for other family members and giving up vacations, leisure time or hobbies. This personal time restriction is greater when needs for care – as in dementia care – are greater (National Alliance for Caregiving and Alzheimer's Association, 1999). This makes ultimate sense – the more time one spends on caregiving, the less time one has for oneself. Other types of negative impacts are less frequently reported. In the NAC/AARP study (National Alliance for Caregiving and Alzheimer's Association, 1999), less than one-quarter reported physical or mental health problems as a result of caregiving. Again, however, these problems were more likely for dementia than for non-dementia caregivers. Accommodations to employment have been reported for up to one-fifth of caregivers. Also, more likely for dementia caregivers than non-dementia caregivers were decisions to change work schedules, turn down a promotion and

terminate employment entirely (Ory et al., 1999). Of important note, few caregivers in ethnic groups reported financial hardships as a result of their provision of care.

There has been considerable attention directed toward mental health impacts of caregiving. Depression and anxiety are the outcomes most frequently studied. Prevalence rates of depression among dementia caregivers have been as high as 43-46% (Haley et al., 1987; Gallagher et al., 1989), nearly three-times the rates found among representative middle-aged and older populations (Eaton and Keisler, 1981; Frerichs et al., 1981). While rates of depression across studies of dementia caregivers vary, the consistent finding is that dementia care is psychologically distressing. The MEHP examined depression among non-dementia caregivers and found a rate of 35.2% or twice that in the general population. A comprehensive review by Schulz and colleagues (1995) has pointed out the bias in such findings introduced by the non-representative samples of most dementia caregiving studies, but also the robustness of the finding that caregiving is psychologically stressful.

The data regarding physical health effects of caregiving, however, are less strong. Caregivers often report their health to be worse than do non-caregivers. However, the results across studies are inconsistent (Schulz et al., 1995). We cannot draw clear conclusions from these data for any subgroup of caregivers. However, those caregivers reporting high psychological distress often also report health problems, alerting us to a potentially high risk group in need of intervention.

No clear conclusions can be drawn about ethnic differences in psychological or physical distress of caregivers. Again, there are inconsistent findings across studies with some reporting no differences in psychological or physical health outcomes and others reporting that White caregivers report more distress and burden (c.f. Calderon and Tennstedt, 1998; Ory et al., 1999). Given that minority elders are more disabled and receive more care, it is reasonable to expect that caregiver burden or distress would be higher. However, research to date does not generally support this. I would caution against quickly assuming that cultural differences (e.g., increased familism or reciprocity) mediate the negative effect of care on caregivers well-being. A recent qualitative analysis in NERI's cross-cultural comparative study raises the possibility that these lower levels of burden in minority caregivers are a product of the measures used in previous studies – measures developed with White populations. This analysis (Calderon and Tennstedt, 1998) reveals that minority caregivers express their distress differently than do White caregivers – using anger, frustration, and somatic complaints – which are not captured in the common measures of caregiver burden. It is incumbent upon researchers to develop culturally sensitive measures of caregiver distress.

This brings us to an area of increasing interest to researchers and one with important implications for service providers. Caregiving is not universally distressing. There are a great many caregivers who report minimal or no untoward effects of their helping role (McKinlay et al., 1995) and describe caregiving in positive terms (National Alliance for Caregiving, 1997). Researchers are now interested in factors that cause distress and, perhaps even more important, factors that mediate distress. It has been commonly assumed that caregiving distress is related to caregiving tasks – the more care provided, the more burden for the caregiver. More recent sophisticated analytical models have shown this not to be true (Schulz et al., 1995; Yates et al., 1999). Neither the disability status or the amount and type of care provided are related to caregiver burden. However, the manifestations of problem behaviors (wandering, hitting, disrobing) associated with AD or other dementias has been consistently related to greater caregiver burden and likely account for the differences between dementia caregivers and non-dementia caregivers in perceived burden.

Because the amount of care provided does not result in caregiver burden, the caregivers perception or appraisal of the caregiving demands has been of recent research interest. The MEHP measured this appraisal using a scale of role overload (Pearlin et al., 1990), which indicates how much an individual feels overwhelmed by the tasks of caregiving, specifically perceptions of exhaustion, having enough time for oneself and to do required tasks of caregiving, and perceived progress in terms of caregiving. The results of the path analysis model (Figure 2) show that role overload was greater if the caregiver provided more hours of care and cared for an elder who exhibited problem behaviors. Further, a caregiver who reported role overload was also more likely to be depressed (Yates et al., 1999). We were interested in what resources available to a caregiver might mediate or buffer the effect of amount of care on role overload and risk of depression. We found that a better quality of caregiver/care recipient relationship, a sense of mastery, and emotional support decreased the likelihood of role overload and, in turn, depression.

A recent qualitative study regarding the experience of control in caregiving (Szabo and Strang, 1999) supports these findings. Control is seen as a factor that influences a caregiver's ability to manage stress and burden associated with the caregiving role. Maintaining control in this study was indicated by identifying internal resources, recognizing a need for help and asking for it, anticipating the future, and taking corrective action when impending loss of control was felt. Lack of control, on the other hand, was reflected by inability to recognize their need or ask for help, not

anticipating the future, and identifying negative internal resources, i.e., lacking confidence in their caregiving abilities.

Several studies, including our work, have taken a more salutogenic approach and investigated how caregivers cope with the daily demands of caregiving. This work offers useful data to inform the development of supportive interventions. Caregivers use a variety of private, personal, or informal methods to cope with stress. The NAC/AARP Survey (National Alliance for Caregiving and American Association for Retired Persons, 1997) reported the following common methods of coping: prayer (74%), talking with friends or relatives (66%), exercise (38%), and hobbies (36%). Sixteen percent had sought professional help or counseling. Most caregivers used multiple coping mechanisms, and, not surprisingly, the number of coping mechanisms increased as the level of care increased and was higher in dementia care.

An important point – with clear implications for intervention – is the degree to which caregivers anticipate and plan for the future. Many studies have found that people do not plan for how and when they will assume a caregiving role (Horowitz, 1985). Instead, it happens to them. Montgomery and Koslowski have conceptualized stages or markers of the caregiving career. For many, this emergent stage is a gradual process in which an adult child provides some assistance (e.g., shopping or home maintenance) before it is essential. As the parent develops functional disabilities, more tasks are taken on. For others, there is an acute or defining event (e.g., a CVA or hip fracture) that thrusts them suddenly and unexpectedly into the caregiving role. This latter situation is more stressful. For some time I have thought that caregiving in a stable situation, while demanding of time and energy, is not necessarily stressful because the caregiver establishes a routine and adapts to it. However, an acute event, whether it is the initial event or an event superimposed on a chronic situation, upsets the routine, requires additional time and energy resources, and therefore is more stressful. An early study by Zarit et al. (1986) showed that caregiver burden diminished over time as caregivers likely adapted to the demands of caring. A more recent study by Given et al. (1999) investigated the effect of new demands for assistance on caregiver well-being. They found that caregivers who experienced high numbers of new demands for care following a hospitalization were more likely than those who did not to experience increased levels of depression. These findings are particularly relevant in the current health care environment in which patients are discharged earlier, once intensive therapy is completed, which increases the complexity of care needed in the home. Limits on Medicare home health visits resulting from the 1997 Balanced Budget Act place more demands on family caregivers. While some policy makers remain concerned with the

availability and willingness of families to provide care, concern should be directed toward their ability and skills to do so.

An important point here again is that increased involvement of family caregivers has long been associated with lower use of formal care services. Data from the NAC/AARP survey (National Alliance for Caregiving and Alzheimer's Association, 1999) are consistent with that of other studies. On average, two services of a possible 10 services were used by caregivers in that study. Service use increases with level of care needed and is higher for dementia care than non-dementia care. However, while it is plausible that use of formal services would alleviate the caregiver's sense of role overload, the MEHP data (Yates et al., 1999) indicate that this is not the case. As shown in Figure 2, service use appeared to have little or no effect on caregiver well-being.

Studies of caregiver interventions, particularly respite care, have shown inconsistent results (Knight et al., 1993; Zarit et al., 1998). Respite care can be provided through in-home services, adult day care, volunteer programs, and brief residential care often in nursing homes. Adult day care has been the form of respite most frequently studied. Caregiver outcomes investigated in these studies include stress, anxiety, somatic complaints, depression, and psychological well-being. Results of early studies showed limited therapeutic benefit (e.g., Strain et al., 1988; Guttman, 1991; Gottlieb & Johnson, 1995; Henry & Capitman, 1995) and results across these studies were inconsistent. However, as described by Zarit et al. (1998), limitations in study design and measurement might have obscured the value of adult day care as respite. The well-designed study by Zarit and his colleagues (1998) demonstrated both short-term (3 months) and long-term (12 months) benefits of adult day care use in decreasing caregiver stress and enhancing psychological well-being. This study also focused on the caregiver's appraisal of the situation (using the same measure of role overload discussed previously), underscoring the subjective experience of caregiving as an important target of intervention.

Another intervention approach – support and counseling – was studied by Mittelman and colleagues (1996). They provided individual and family counseling followed by support groups for spouse-caregivers of elders with dementia to see if it resulted in delaying nursing home admission. The intervention was successful in prolonging the time that these caregivers provided care at home, particularly during the early to middle stages of dementia.

These recent data support an upstream approach (McKinlay, 1975, 1996), in which one attempts to intervene before an issue becomes a problem too difficult to solve, would focus on the contributors to overload and attempt to intervene in a way that prevents stress rather than simply relieving it. If we consider the recent findings

regarding a caregiver's appraisal of their situation, upstream interventions might address issues of evaluating the elder's needs, coming to terms with the needs of the elder versus the caregiver's ability and willingness to provide care, and developing strategies to prevent overload, by training caregivers in technical skills or in obtaining emotional support before they actually need it. The challenge here is to identify caregivers and intervene perhaps before they identify themselves as caregivers, or perceive the need for outside intervention.

Finally, we turn to cessation of the caregiving role. Very few studies have investigated why caregivers voluntarily leave the caregiving role (i.e., for reasons other than institutionalization). Using national data from the National Long-Term Care Survey, Kasper et al. (1994) found that ending caregiving occurred for only 5% of cases and was related to higher levels of care, need for constant supervision, caregiving for less than one year, and a sense that good feelings did not outweigh caregiving stress. It was also more common in caregivers who were not closely related to the elder. Analysis of this question in the MEHP data revealed that cessation of caregiving was related to manifestation of problem behaviors, not having a good relationship with the care recipient, lack of confidence in ability to provide more care, and not being a close relative.

Implications for Policy and Practice

Major findings with important policy and practice implications include the following:

Patterns of Care

- *While family care is very common, most of the care is provided by one person.*

Contrary to common assumption, there is little sharing of care. Even in cases where multiple caregivers are involved, they tend to supplement the care provided by the primary caregiver. We see little division of labor. Given that restrictions on personal and leisure time is the most frequently reported caregiving impact, working with the primary caregiver to identify both other informal and formal sources of care to provide respite in a timely manner is indicated. A second point is that we should not take for granted that minority elders have larger caregiving networks. Hispanic elders are a case in point. As the largest growing minority group and the most disabled in later years, Hispanic elders face social situations that could diminish caregiving resources – smaller family size, increased employment of women, and the economic necessity of living at a distance from adult children. Given a strong sense of familism, these adult children face considerable challenges if trying to provide care in light of these social circumstances.

- *Family care is generally stable. Few families voluntarily abandon their role in favor of community services or institutional care.*

Research data do not support the policy concern that families will stop caring if more publicly funded services are available. Yet we do see disruptions in the informal care arrangements which result in increased service use on a temporary basis. I would argue that this is an appropriate and effective use of community services. Agencies should be sensitive to and prepared to respond in order to divert an undesirable nursing home admission. Research data can be used to develop client profiles to target service to at-risk elders.

- *Most caregivers are women. However, in the case of spousal caregiving arrangements, men are highly involved.*

More attention should be directed to situations in which the primary caregiver is male, particularly if the care recipient requires extensive and personal care. Male caregivers in these situations are usually older. This current cohort of older men is least likely to be prepared and skilled to provide a range of help. They might also be challenged by their own health conditions or physical disability. These situations merit special attention. Men want to care for their wives but may need skill training or supportive services (especially personal care) in order to do so.

Impacts of Care

- *The care of disabled older adults can be burdensome, but caregiving stress is not universal.*

For many caregivers of elders with dementia, caregiving is emotionally and physically stressful. Yet, data from studies of caregivers of elders with functional disabilities indicate that, other than the shared restrictions on personal and leisure time, caregiving is not generally perceived as stressful by most caregivers. From a policy perspective, it is important not to generalize the findings from studies of dementia caregivers to non-dementia caregivers and vice versa. Doing so would likely result in over- or under-estimates respectively of the need for support and services. The strains and needs of both groups of caregivers should be acknowledged yet clearly distinguished for at least two reasons: 1) to accurately identify how best to assist caregivers in each group since their stressors, perceived stress, and resulting needs may differ; and 2) to more accurately estimate the demand for long-term care and caregiver support services, both types and amount.

A second point – I strongly caution about accepting research findings to date that minority caregivers are less burdened than White caregivers, that they are more resilient and have more resources to meet caregiving demands. Researchers must evaluate the sensitivity and cultural appropriateness of commonly used measures of caregiver distress to ensure that these measures are not underestimating the stress experienced by minority caregivers.

- *Physical and emotional well-being of caregivers is influenced not by the type and amount of care they provide but rather by their appraisal of that care.*

If caregivers feel overwhelmed or overloaded by their caregiving responsibilities, they are more likely to experience physical and especially emotional problems. It should not be assumed that all caregivers providing extensive care to severely disabled elders are burdened, or that services to offer respite are the only answer. The assessment of at-risk caregivers should be directed at their feelings about their caregiving responsibilities – their ability to manage multiple demands, their confidence in their caregiving skills, their organizational and time management skills – rather than on what they do.

- *Caregiver well-being is enhanced by a sense of mastery, the quality of the relationship with the care recipient, and feeling supported in the role.*

Caregivers use a wide variety of coping mechanisms. Interventions that take a salutogenic approach – develop caregiving skills and coping skills and mobilize sources of informal support – are likely to show more therapeutic benefit than ones taking a pathogenic approach of trying to relieve burden.

- *Dementia caregiving should be distinguished from non-dementia caregiving.*

Dementia care, particularly at advanced stages of disease, is undoubtedly stressful. The manifestation of problem or disruptive behaviors is particularly stressful. Developing interventions to specifically address these behaviors by changing the elder's behavior or by developing the caregiver's skills to manage the behaviors is indicated (Schulz et al., 1995). Intervention protocols, some of which are now underway and being evaluated, include skills training, education, and counseling. As pointed out by Schulz et al. (1995), since the dementia patient is usually the contact person with the service system, patient assessments offer an opportunity for assessment of the caregiver's status as well.

- *Formal services are used infrequently.*

Although economic constraints have limited service availability in recent years, even when services were more widely available in the early 1980s, they were not widely used. In general, services are targeted on the basis of extent of need for care and availability of informal sources of care. Assessments typically are care recipient focused. Research data support more attention to assessment of the caregiver's status. Again, assessment is better directed at the caregiver's appraisal of the caregiving arrangement rather than at the caregiver's availability and physical ability to provide care.

In the case of dementia care, use of formal services is not only appropriate but also clinically indicated as severity increases. From a practice perspective, it is important to determine the optimal mix of formal services and informal care in order to ensure the well being of both care recipient and caregiver. Transition to a special care environment is another important juncture in this regard. Assistance with appropriate timing and with negotiating a role for continued involvement of the caregiver(s) will facilitate what might be interpreted as another in a series of losses by a caregiver who sees this transition as loss of an important role.

From a policy perspective, the issue of eligibility criteria for services is important. For both publicly and privately (i.e., third party payer) funded services, eligibility typically is based on functional disability in the performance of specified ADLs. The Advisory Panel on Alzheimer's Disease (1989) has advocated for the expansion of eligibility criteria to provide services in situations where the degree of cognitive impairment interferes with the person's ability to complete either IADLs or ADLs without substantial supervision. The cost analyses performed by Paveza et al. (1998) "suggest that changes in cognitive impairment are independent factors affecting cost regardless of the magnitude of ADL/IADL impairment" (p. 79). Similar findings from the National Long-Term Care Channeling Demonstration Project in the 1980s were reported by Liu et al. (1990). These findings support the notion of applying a cognitive weighting factor to the degree of ADL/IADL impairment in establishing eligibility for services.

- *Most caregivers do not plan for the future. Unexpected acute events are stressful.*

Not only do most adults not plan how they will provide care for their parents or other relatives, most caregivers also do not plan for changes in caregiving needs. A common coping strategy is to "take one day at a time." This works as long as the situation is stable, or changes gradually. A major acute health event which suddenly increases the need for care is an appropriate time for formal intervention. This may be organizationally challenging for service providers since services might be needed quickly

and at times when services are not normally provided. However, all the research data on well-being of both care recipient and caregiver indicate that these services are needed and will likely have a beneficial effect.

An alternative approach is to engage a caregiver in mutual planning for handling of such situations. This is challenging, as most people will not seek out information until they need it. General information sessions about community services are frequently not well attended. The most effective strategy might be to engage a caregiver in planning shortly after experiencing an acute event. The recent experience might sensitize them to the need and increase their receptivity to new information.

Finally, the challenges we face as we approach the millenium include:

- The widely recognized changing sociodemographics of the older population – the aging baby boomers;
- Projected changes in active life expectancy and the compression of disability, meaning higher needs for care but perhaps for shorter periods of time at advanced ages;
- The availability and ability of families – which will be smaller and older – to care for very old and perhaps severely disabled elders; and
- The increased ethnic diversity of the population, underscoring the need for culturally sensitive and appropriate services and service delivery mechanisms.

In closing, we should not lose sight of the fact that caregiving is imbedded in the family experience, history, and values. How caregivers respond to the presenting needs for care, how they perceive the personal impact of that care, and how they interface with the formal service system will be shaped by their personal situation. As we have argued for recognition of the heterogeneity of older adults, in all that we do as researchers, practitioners, and policy makers, we must recognize the heterogeneity of their caregivers.

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Table 1
ASSISTANCE WITH INSTRUMENTAL ADLs

Transportation	79%
Grocery Shopping	77%
Housework	74%
Meal Preparation	60%
Managing Finances	56%
Arranging/Supervising Outside Services	54%
Medications	37%
No IADL Assistance	2%

National Alliance for Caregiving and AARP, 1997

Table 2
ASSISTANCE WITH PERSONAL ADLs

Transfer in/out of chairs	37%
Dressing	31%
Bathing	27%
Toileting	26%
Feeding	19%
No PADL Assistance	49%

National Alliance for Caregiving and AARP, 1997

Table 3
ANNUAL COST COMPARISON (in 1991 DOLLARS)
MASSACHUSETTS ELDER HEALTH PROJECT

☐ Informal Care and Formal Services:	\$9,552	\$16,752
with living expenditures:		
☐ All Formal Services:	\$13,799	\$20,999
with living expenditures:		
☐ Nursing Home Care	\$35,522	

Harrow et al, The Gerontologist, 1995

Table 4
IMPACTS OF CARE

	Dementia Caregivers	Non-Dementia Caregivers
☐ Less time for families	56%	40%
☐ Had to give up vacations, hobbies, own activities	53%	40%
☐ Physical or mental health problems	23%	12%
☐ Changes in Work Schedule	57%	47%
☐ Change in Employment	Up to 13%	Up to 11%

National Alliance for Caregiving and Alzheimer's Association, 1999

Table 5
ECONOMIC VALUE OF INFORMAL CARE
COMPARED TO NATIONAL EXPENDITURES (1997)

🏠 Home Care	\$32 billion
🏠 Nursing Home Care	\$83 billion
☐ Informal Care	\$196 billion
☐ Total Health Care	\$1,092 billion

Arno et al, Health Affairs, 1999

Figure 1
Amount of Care From Informal and Formal Sources
by Level of Frailty

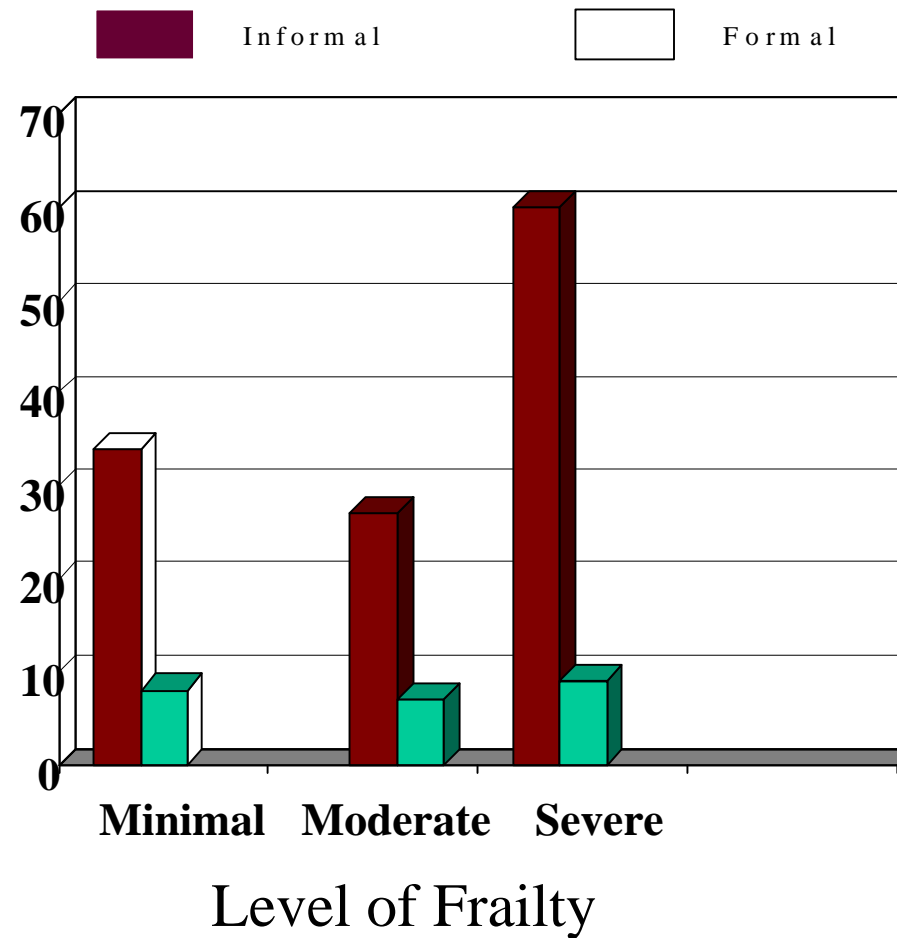
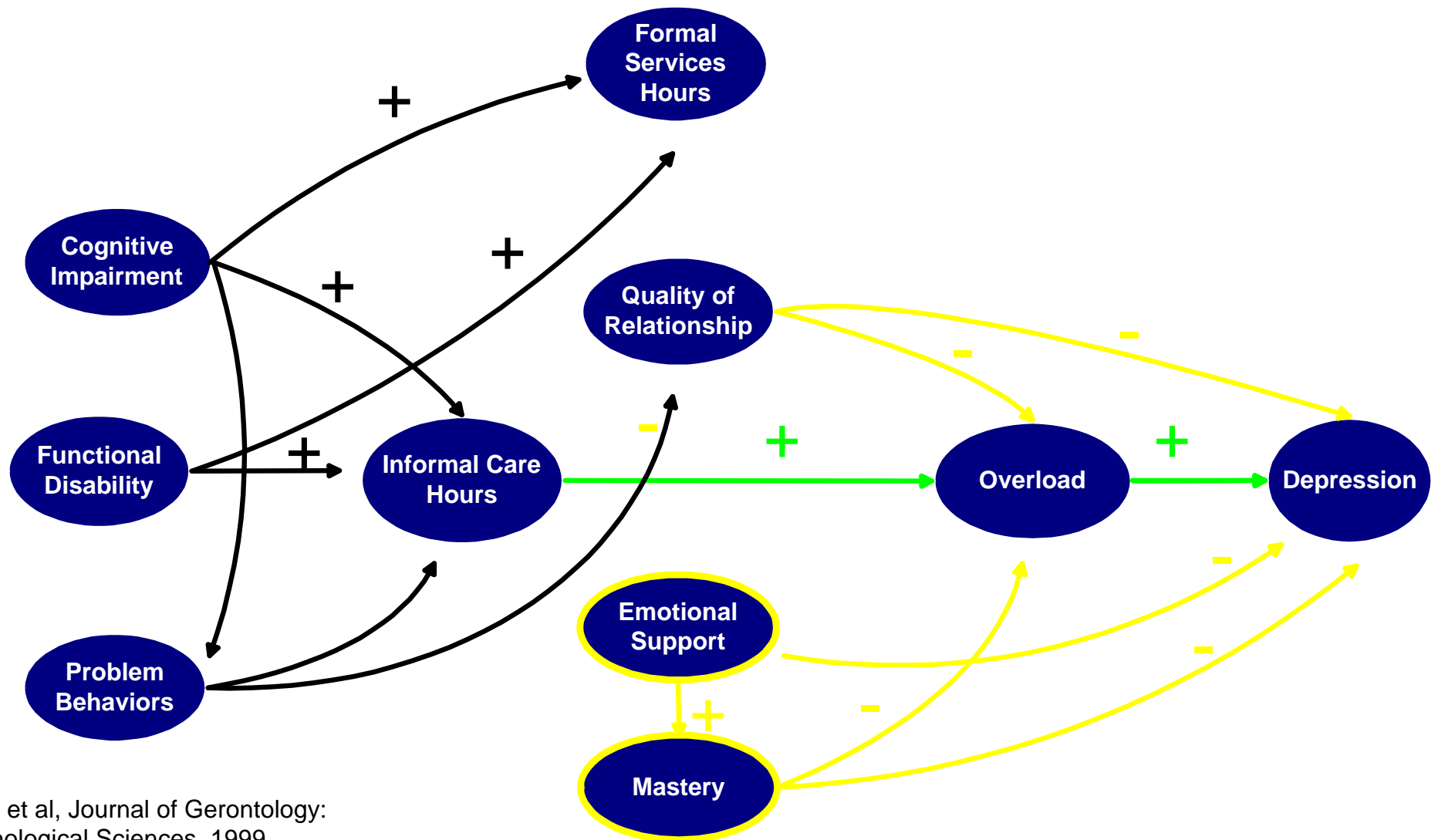


Figure 2
Contributors to Caregiver Well-Being



Yates et al, Journal of Gerontology:
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